

Message Text

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E.O. 11652: N/A

TAGS: TPHY, TBIO, IT

SUBJECT: REQUEST FOR MEDICAL INFORMATION

REF: PALERMO 274

1. NATIONAL INSTITUTE OF NEUROLOGICAL AND COMMUNICATIVE DISEASES AND STROKE (NINCDS), NATIONAL INSTITUTES OF HEALTH (NIH) ADVISES MORE CLINICAL INFORMATION NEEDED ON 7 YEAR OLD CHILD SUFFERING FROM MUSCULAR DYSTROPHY (MD) IN ORDER TO COMMENT IN DETAIL, AS THERE ARE MANY FORMS OF DISEASE. FOR EXAMPLE, MYOTONIC MD BEGINS IN INFANCY AND DUCHENNE MD USUALLY APPEARS BETWEEN AGES 2 AND 6.

2. THERAPY OF ALL MD IS PRESENTLY PALLIATIVE AND NO CURE OR TREATMENT EXISTS TO ARREST PROGRESSION OF DISEASE. NINCDS SENDING SEPARATELY MORE DETAILED INFORMATION ON CURRENT METHODS OF TREATMENT.

3. NINCDS HAS ACTIVE CLINICAL RESEARCH, REPEAT RESEARCH, PROGRAM ON NEUROMUSCULAR DISORDERS, INCLUDING MD. IF UNCLASSIFIED

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CHILD'S PARENTS INTERESTED IN HAVING CHILD CONSIDERED FOR PARTICIPATION IN STUDY, PAMPHLET ON PATIENT ADMISSION PROCEDURE BEING SENT SEPARATELY SHOULD BE FOLLOWED. CHILD'S PHYSICIAN MUST DESCRIBE REFERRAL IN DETAIL AND PATIENT MUST FIT NINCDS CLINICAL RESEARCH PROTOCOL. FAMILY MUST ASSUME TRAVEL EXPENSE AND MUST UNDERSTAND THAT THIS IS FOR RESEARCH ONLY AND NOT, REPEAT NOT, TREATMENT.

4. NINCDS ALSO SUPPORTS CLINICAL RESEARCH CENTERS ON MD
AT WASHINGTON UNIVERSITY IN ST. LOUIS, UNIVERSITY OF
PENNSYLVANIA, COLUMBIA UNIVERSITY AND DUKE UNIVERSITY.
FURTHER INFORMATION ON NINCDS RESEARCH PROGRAMS AVAILABLE
FROM DIRECTOR, NINCDS, NIH, BETHESDA, MARYLAND 20014. VANCE

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